Live captioning by Ai-Media   
  
JESSICA PODESVA:   
Hi everyone! We are going to get started in just a couple minutes, we're going to let folks trickle in. It looks like folks are still joining. We will get started in a minute.   
  
THEO BRADDY:   
Is this automatically be recorded?   
  
JESSICA PODESVA:   
We are going to hit play in a minute.   
  
THEO BRADDY:   
Toasty Phoenix.   
  
(Recording in progress)   
  
JESSICA PODESVA:   
I'm going to give it another minute because I still see folks joining.   
  
Alright, going to go ahead and get started.   
  
Welcome everyone, I'm so excited to see so many people join us today. I wish it was for a better reason, but this is a call to action. It's really great to have so many of you join to help us get this message across.   
  
My name is Jessica Podesva I'm the director of advocacy at the national Council for independent living. I am a white woman with long brown hair wearing a black shirt and glasses. I use she/her pronouns.   
  
We are here today because unable 26 the US House of Representatives passed the limit, save and grow active 2023. This bill would cause deep cuts to discretionary spending, or until the debt limit reaches 1.5 trillion, whichever comes first. The bill imposes radical work requirements for Medicaid enrollees ages 19-95 in exchange for lifting the Debt Ceiling, and this could result in millions of people losing their Medicaid benefits. It also expands the current requirements for SNAP and (Unknown Term) programs.   
  
So we are here today is a call to action. We will hear from a couple consumers on how Medicaid is so vital to them accessing their Home and Community-Based Services. We have over 650,000 people currently on home and community based services waiting lists.   
  
Medicaid needs to be expanded and not cut. Soberly today, we are going to talk about reasons why, and we are going to be recording this so we can share it far and wide.   
  
Then if we have time, we want to hear from you all.   
  
So without further ado going to go ahead and turn it over to our Executive Director Theo Braddy want to say a few words to get us started. The L.   
  
THEO BRADDY:   
Thank you Jessica. This is important to me for so many different reasons. Obviously I'm a person with this ability as well.   
  
Again I want to welcome everyone, my name is Theo Braddy, Executive Director with Nickel.   
  
So why are we here? The programs that does the most good are the ones that Republicans would try to cut. That's historical. And we know how important these programs are. Medicaid programs, we know that. We live it out every day.   
  
But this is the biggest excuse to do what they always wanted to do. They're going to say it's necessary so the US doesn't fall. That's what they're going to say, we know that. That's how people can do evil things and dress it up as good.   
  
So we have to fight this, we have to fight it right now. We have to act and stop these cuts. They are trying to take advantage of people with disabilities work eight hours a month. -- We know people with this ability want to work.   
  
That eight hour requirement work has nothing to do with why employers and society don't want to hire people with disability. We all know that. There are other factors that prevent people with disabilities from working. Alright?   
  
So our voices must be heard. You can't sit on the bench on this one. You have to get in the game and you have to act right now.   
  
There are other options that can be done other than cutting Medicaid. We know that.   
  
They could easily, easily, slightly increased taxes for those with the most. Those rich folks with all the money. They could easily do that. But they are saying that it's off the table. We have to make sure they know cutting Medicaid is off the table too.   
  
Go ahead Jessica.   
  
JESSICA PODESVA:   
Thank you so much Theo.   
  
Our first speaker today is Richard Anderson who is a consumer in Norman Oklahoma.   
  
RICHARD ANDERSON:   
Hi.   
  
Thank you Jessica for inviting me to speak in this event.   
  
I'm Richard Anderson, chairman of Oklahoma adapt, and today I want to talk to you about employment and Medicaid.   
  
What is employment? Is it something that keeps you busy? Is it something keep you active? Is it something that shows the compliments from your education? Is it something that keeps you learning and getting better? Is it something that keeps you alive and engaged with society? Is it something that defines who you are? And like it or not, employment also tells society something about you, or perhaps it's all of those somethings that I just mentioned.   
  
So, I think we all can agree that employment is a big part of everyone's livelihood, while also sustaining a healthier mental and physical outlook.   
  
In America, there is a saying that is used a lot, and it is: "If you work hard, you can be and do whatever you want."   
  
I bought into that great sounding American motto throughout my childhood. I never thought of myself as having a disability, nor was I treated any different until I hit my early 20s, and it was then I realized the motto was not totally true, at least not for those who have a physical disability who achieve a higher education and skills to maintain a computer desk job like I have.   
  
I found my first job listing the Norman transcript for a position with the city of Norman in Oklahoma doing data entry in 1988. This could not have been any more perfect for me. Perfect location to where I live and still do.   
  
I just graduated from more Norman   
  
GEORGE RECKTENWALD:   
Tech were studied for two years for that particular position, and so on.   
  
Two weeks after applying,   
  
-- Three weeks after applying about over to the city to see about the position because I haven't heard from them. The lady working there literally told me I didn't get the job because I was overqualified.   
  
Overqualified, fresh out of (Unknown Term) tech.   
  
Knows what the real reason was, but overqualified...   
  
I highly doubt that. It was two years prior (Indiscernible) and I was young, so I didn't know what to do or have the guts to confront like I do now.   
  
When the ADA law became effective on July 26, 1990, finally, the tables will turn in our favor for implement. Like tax incentives for companies to hire us, along with other great things.   
  
To make a long story short, it did not others and cause (Indiscernible) things.   
  
I finally got a job doing web design in a local Internet company in 1998 with the help of Oklahoma universities supported employment program. And in 2000, the Internet company got bought out, and then I was laid off shortly after.   
  
I've been unemployed ever since due to the lack of a good supportive and will -- supportive implement program since the state cut programs University program.   
  
During my diploma time, I dove into other career opportunities since web design was moving to an in-house part of companies had more intense programming. I started focusing on sharpening my skills in graphic designing. Because while doing web design, we had to design and work with graphics, which I took a liking to.   
  
In 2023, sadly people with physical disabilities with great education, skills, and her job ready, still have a hard time getting suitable employment that are aligned with their education and/or skill level.   
  
Yes, there are organizations that help people with disabilities was getting employment, but they mainly cater to those with developmental disabilities with low-end job skills, which they are highly equally important.   
  
However, this is leaving the ones who could (Indiscernible) high-end job unemployment and government (Indiscernible) which we do not want.   
  
Now here is where the Medicaid buy-in program comes into play. This program allows eligible individuals to buy into the Medicaid program ensuring us to receive the necessary healthcare and financial assistance to maintain employment and achieve our goals.   
  
If you are lucky enough to land a good job with good pay that complements your education level and/or skill level, you're losing a very important part of your government benefits. Your Medicaid.   
  
It lets you live in a state that offers Medicaid buy-in program. Some think that a person with disabilities really needs to even be employed. Because Medicaid covers things most employer insurance doesn't cover. Such as personal care attendants, medical equipment, like wheelchairs, walkers, the list goes on and on.   
  
Most of you are probably wondering how I work in 1998 without Medicaid? I didn't.   
  
Since it was my first real job, I chose to make last -- less pages to make my will may look good for future employment opportunities, but that never and couldn't have happened anyways, and frankly I'm glad it didn't. Because I would have been making too much as a graphic designer to stay on Medicaid, and I wouldn't -- taken a pay cut again knowing local, should have them etiquette buying program in place in the early 2000's.   
  
The American government needs to cease its failure in supporting us in entering our progress with excessive dependence on government assistance. Moreover, it should abandon its tendency to undermine a crucial safety net upon which many Americans with disabilities will I chose to sustain their lives.   
  
Instead of solely focusing on budget cuts for specific safety net programs like the Republic -- republican's are doing right now, both America and it states must take decisive action to redefine strategies that facilitate the employment of all individuals with disabilities without subjecting them to penalties.   
  
It's imperative that American mandates all states to uniformly implement the Medicaid buy-in program. Ensuring that we receive the necessary support to maintain employment, advance in our careers, or simply engage in meaningful work where we live. And wherever we want to move to.   
  
The last no longer be restrained by outdated policies lack relevance in the present day, letter wall -- let alone two decades ago.   
  
Pictures is, on government assistance, today I make my hundred and $55 per month -- $955 per month when I started getting government assistance when my mom passed away in 1985. It was $406 per month. 38 years later, I am still living in poverty.   
  
Has of May 15, 2023, the average annual pay for a graphic designer in Oklahoma is $51,091 a year. Just in case you need a simple salary calculation, that works out to be approximately $24.56 an hour. $582 a week. (?) $982 a week, â€“ the monthly income is around $4257.   
  
In the last 23 years, if Oklahoma would have implemented the Medicaid buy-in program, I would have been off of government assistance and paying for my own Medicaid through the Medicaid buy-in program, as well as other people with disabilities.   
  
Not only would we gain a fulfilled life, the state of Oklahoma would make more revenue from purchases and taxes for me, and I am only one.   
  
There are a lot of people who can, or want to seek employment due to the lack of the Medicaid buy-in program.   
  
Bottom line, we did what we were supposed to do to not be government dependent, now we need the American government on all levels to step up and on up there and to make sure we are.   
  
Thank you.   
  
JESSICA PODESVA:   
Thank you so much Richard, that was really powerful.   
  
I think it hits on a really important point about this bill, requirements don't work and they are based on a false narrative that people who are receiving benefits don't have any incentive to work, and that could not be further from the truth.   
  
Thank you very much for sharing your story with us today. And I know that many people have had similar experience is.   
  
Next up we will hear from Lori Taylor.   
  
LORI TAYLOR:   
Hello.   
  
JESSICA PODESVA:   
Hey Lori. There you go, you're all set, thank you for   
  
LORI TAYLOR:   
Hi, my name is Lori Taylor, I also live in Norman Oklahoma.   
  
Unlike Richard, I was very fortunate early early in my life to get a job and maintain it.   
  
I started off as a dispatcher at a not-for-profit organization. And I worked my way for the next 30 years up to technical support for Apple.   
  
During that time I did not rely on the system at all. I got off of SSRI, I got off of Medicaid, Medicare, I got off of all of it. And I did well. I met a man, we moved away out of state, and I was able to thrive.   
  
Well unforeseen circumstances happened, and I was forced to leave the state of Colorado which did have Medicaid expansion. Over to Oklahoma. Where my family is. This is where I'm born, Michael roots are here, everything I learned is here.   
  
And so I came home for family support. Because I didn't have my husband anymore, I needed someone to help me with my daily activities. Personal care that he used to do for me, but now I had nobody. Nobody except my family.   
  
Now it is very hard to go from 17 to 49, being independent to relying on your mother to tuck you in bed at night. I didn't like that, I worked very hard to get out of that.   
  
The reason I am here today is because the state of Oklahoma's rules and their refusal to expand Medicaid, or anything, allow Medicaid buy-in, would have been perfect for me because I was independent, I did have insurance through my work, but it didn't cover everything my disability required.   
  
There was a point in my employment where I needed a wheelchair replaced. And I have an electric chair. I cannot go through my daily life, or keep my job, if I do not have my chair.   
  
The insurance I had for my company would not pay for one, they refused. I fought for over a year to try to get it replaced, they refused.   
  
I was pushed in a position where I was going to have to quit my job, go on government assistance, get Medicaid to buy my chair for me, and pray I could get a job again someday.   
  
I didn't want to do that, and my employer didn't want me to do that. I worked in a great big call center. There's about 500 employees there. And vendors that we used. And they all pulled together, and they came up with the many -- with the money and they bought mature. Now who's have been lucky to have that happen to them even once in their life?   
  
That is why I need Medicaid. It covered things insurance didn't.   
  
Such as a personal home healthcare aid. That and my wheelchair are the most important to me in living and dying.   
  
Now because of the lack of Medicaid expansion or buy-in in Oklahoma, I was forced in order to receive Medicaid that will pay for those things, I had to be on disability. In order to be on disability, I couldn't work. So I was forced to quit my job, which I did grudgingly.   
  
I had a COVID proof job. I worked at home, on the computer as tax -- Aztec support as a member of Apple. How much more better can you get? My job follow me, that was ideal.   
  
Anyway, soon after I got all set up, I got my disability, I got my home health and care made, I got my own (Indiscernible) out of my mother's house. I received a letter in the mail, along with all the other disabled people in Oklahoma, saying "You have 30 days with your personal healthcare with this advantage program that takes care of it, which is part of Medicaid."   
  
They were going to cut it. They were going to stop it. We had 30 days for our whole community, and when I say community, I don't just mean the disabled person. I mean the people that work for them. I mean the daycare centers, I mean the interpreters, everybody. Nurses, doctors, everybody. Everybody was going to be affected by this.   
  
So we fought and we finally got them to stop that. And why I am here today is to plead and beg for some mercy on the lowest wrong -- wrong of what you appear to be the lowest wrung of society.   
  
We are human beings, we don't deserve this. These programs, Medicaid, is life and death to us. The only alternative is discrete, or to die slowly in a -- the street, or die slowly in a nursing home or your home.   
  
You can't cut this.   
  
If you want to weed out people taking advantage of it, fine, but that's a very small number of people. People depend on this. Cuts will be devastating, you're going to kill people. Please, listen! And have a heart! I'm begging you!   
  
If you do Medicaid cuts, you're going to kill people. If you do Medicaid expansion, you can't imagine the return you are going to get. People are going to be able to live, and work.   
  
We aren't deadbeats. We are smart. We have skills, we have thoughts, we have feelings, we have people who love us. You are hurting everybody by doing this.   
  
If you want to make money, tax the rich people who refused to pay. We aren't asking them to give away their riches, pay your fair share!   
  
It's not fair that we take it. It's not fair you go off on the yachts and fancy dinners while we are suffering, dying in beds. That's not fair. We want to contribute.   
  
This is a human right. We have a right to exist, and we do. Whether you like it or not.   
  
We need help. We aren't asking for a handout, we are asking for a hand.   
  
In the words of one of my favorite people who have ever lived, get your knee off our net. Cuts are going to kill. Please.   
  
I'm finished now, but please listen. Thank you.   
  
JESSICA PODESVA:   
Thank you so much Lori. That was incredibly powerful, thank you.   
  
You know, it seems really simple that the Republicans are asserting, will sadly, people with disabilities and caregivers will be exempt from this.   
  
That couldn't be further from the truth, and over certifies an incredible week obligated -- incredibly complicated policy and process, and it's fundamentally flawed, identifying what specifically qualifies as a disability. Ensuring people know how to request these exceptions. All of the red tape that this will create will do exactly what Ray just said, and it will cause people to lose their vital access to healthcare coverage, and people will either end up dying or ending up in institutionalized settings which is not what we want for our community.   
  
As Lori said, this is a human right. People with disabilities deserve to exist, deserve to live. Lori, you said it perfectly, I'm not even going to try to tie that up anymore.   
  
Yes?   
  
SPEAKER:   
Lori just wanted to say one more thing.   
  
JESSICA PODESVA:   
Sorry, go ahead Lori.   
  
LORI TAYLOR:   
If I may, I want to add one more thing to anybody who is listening to this.   
  
Disability, the disabled community is a community you consider minority. But think about one thing. It is the largest minority on earth, and is the only one you can join at any moment of any day. You may need this someday. Or someone you love may need this.   
  
Just remember, someday it might be you. So please, karma. Thank you for   
  
JESSICA PODESVA:   
Thank you Lori, sorry I missed your message in the chat.   
  
Our next speaker is a nickel board member Sam Marino. Sam.   
  
SAMANTHA MORENO:   
That's hard to follow up on that one. I feel like I could persevere and all that, that's hard because it's true.   
  
Anyhow, it's just amazing to see how many people are here. I was scrolling through all the videos, all the cameras and stuff. Just seeing everybody. It's so cool that we are all on this call together, all on this rally. I'm sorry we can't all be in person, but I think this is really impactful. And I really appreciate everyone staying here.   
  
Like Jessica said, I'm Samantha. I serve as the region state representative for the national (Indiscernible) on living. I'm also a member of the healthcare subcommittee for Nickel, so I hear about all the things you are talking about all the time. And we are always trying to do more.   
  
Just for a discussion, I'm a white woman with short to medium length brown hair, I have dark red glasses on and a blue T-shirt. And you can kind of see my office in the background, and various dogs running through the background probably.   
  
So just summing up kind of what Richard, Lori have already said. It seems like we are always fighting for her life. We are constantly fighting, and even after we win, it is a continuous battle just to keep what we already have.   
  
Year after year our rights are whittled away.   
  
So Medicaid is the only program that promotes independent living. It is the only program that funds long-term Home and Community-Based Services. It is also the only program that provides funding for those of us who want to transition from nursing facilities to our own home.   
  
Recently, the House of Representatives passed a bill that will include work requirements and only to receive -- in order to receive Medicaid services.   
  
For years we had been told the exact opposite. Like Lori was saying and Richard was saying. I have done whole speeches and been on panels where we discussed how income affects our benefits. We are told if we work too much we will lose our benefits. And without the support we can't work anyway.   
  
Some states are better than others. I personally work in Oklahoma, but Oklahoma doesn't have the Medicaid buy-in program. I live in Texas. Texas has the Medicaid buy-in program. So I can work and receive assistance and pay for my personal care service.   
  
Without those services, I would have to quit my job since my SAS (?)-- I would have to quit my job since I need personal care assistance.   
  
Allowing these requirements, so they are talking about (Indiscernible) causing thousands of people to lose health insurance. We are dangerously close to losing a lot of what we already fought for.   
  
Medicaid, it is important to know I think Medicaid was designed to help people with limited income and resources to maintain our health. It was not meant to be contingent upon employment.   
  
So what can we do? That's why we are here right? What can we do about this right now?   
  
What we can do is call our state representative. We can call our members of Congress and tell them that we don't want Medicaid to be cut at all, and we don't want casework requirements to happen. It's not necessary, and it is only going to hurt people. If you need help finding out who to talk to, or if you need help figuring out how to say what you want to say and you want to run it by somebody, let us know. We can help you with that. We can help you find your states are presented. Don't let that stop you from seeing what you are going to say. Mike from what you want to say.   
  
I think that's all I wanted to say, I'm just so worked up right now. I'm sorry my voice is all shaky. It's just really powerful thing everybody here. Thank you.   
  
JESSICA PODESVA:   
Thank you so much Sam.   
  
Theo you had a couple of words he wanted to share before we wrap up.   
  
THEO BRADDY:   
Yeah.   
  
I heard some powerful words. I really did. And I can hear the passion behind each one of you all. As we struggle together to make these changes.   
  
So you have your marching orders. You need to contact your legislator. You need to take action right now. You also need to challenge other people you know, peer influence to do the same thing.   
  
They have to hear from us.   
  
I'm going to put in the chat, because I know other people want to provide the testimony. So we are going to use technology to allow you to create a video testimony. So that I'm going to put in the chat, you just follow that any will allow you to put forth a three minute video.   
  
But the most important thing right now is to contact your legislators. And we would use those videos for other kind of advocacy as well, but mainly right now we need the legislators to hear no more cuts, no work requirement. How Medicaid is affecting your life.   
  
If they cut it it's going to affect not only your life, but like Lori said, it's going to affect a lot of other people's lives.   
  
So thank you, and look at that link, and that's all I have to say.   
  
JESSICA PODESVA:   
Thank you so much Theo, you all are making my job really easy.   
  
You heard it from Theo, we need you to contact your representatives. Nickel recently put out an action alert. If you have any questions about who is your member of Congress, who to reach out to, you can click the button and it will take you a link to look it up.   
  
I also want to let everyone know tomorrow that disability and 80 collaborative of which Nickel is a member will be hosting another rally where there will be Senator Casey speaking, and I believe there will be some other folks from some Republican offices. So please, we're going to be sending out information right after this meeting tonight. Please get the word out and ask folks and send it out to your consumers, to members of (Indiscernible) or friends and family to attend.   
  
And really, the louder we are the better. So please just help us get the word out. This really was a call to action.   
  
We have a little bit of time so I can open it up to a few questions if folks have any questions or anything they want to add. We have a little time left, but if you can keep it to around three minutes in case there is a long line of people that want to speak. I already see some hands.   
  
Hello, good to see you!   
  
SPEAKER:   
Good to see you, sorry for being late.   
  
Medicaid individuals and forcefully are now being put on the butter of the wrong -- the wrung.   
  
The best thing you can do is contact independent living centers in your area. Find out how you can get involved.   
  
And the state recommended the organizer for the state of (Indiscernible) at CF I'll see -- CFILC.   
  
Each state is different, we are trying to help individuals gain their independent and guiding them through life. That's all about that. The key for the powerful stories we've heard.   
  
JESSICA PODESVA:   
Thank you and thank you for joining us today.   
  
And yes that is a good point. Centers for independent living are a great resource. If you aren't involved with your local center, and we probably have many center staff here today. If you're a member of the community and not involved with your local center, we highly encourage you to get involved. If you aren't sure who your local center is feel free to reach out to us at capital and we will connect you.   
  
Any other questions or comments from folks?   
  
SPEAKER:   
Can I jump in?   
  
SPEAKER:   
Go ahead Aaron, Theo we will let Aaron go this time for top   
  
(Laughter)   
  
AARON BAIER:   
I just want to say thank you to all the speakers.   
  
My name is Aaron Baier, I'm the repetitive covering region two on the nickel board.   
  
Along with reaching out your Congressional Leaders, your state senators, reach out to local media. Local newspapers, radio stations, work with your local ILC to get contacts with these places. Get the word out in your local community.   
  
As many of you know Medicaid impacts a huge number of people. People with disabilities being a massive part of that. I think others want to hear how this lab would impact the lives of their loved ones. For families. We really need to make sure this word hits the bigger communities as well. Take your stories and get them out there, have an interview with a local DJ, something. Get it out there.   
  
JESSICA PODESVA:   
Thank you so much Aaron.   
  
Seo did you want to say something before we call in our next couple of questions?   
  
THEO BRADDY:   
Yes, real quick. It was just a great chat comment.   
  
The person says I'm trapped in a nursing home, I fought hard to transition into the community. It took me years to obtain the community based services and support I have now in order to live in freedom and independence. I rely on Medicaid, without it I am trapped dead. I just wanted to make sure that was highlighted.   
  
JESSICA PODESVA:   
I think that really speaks to our main ask, which is to tell Congress to stop using our lives as a bargaining chip. Thank you for catching that in the chat.   
  
We have a question from the phone, the last numbers are 7673.   
  
SPEAKER:   
Hi, my name is Doris Ray, Erik and the independent center of northern Michigan (Indiscernible) Washington suburb. In Virginia.   
  
Wanted to ask, after reading the materials if I understand where the bill is right now. It's past the house. It sounded like to me we need to be contacting US senators, unless it somehow gets incorporated into debt ceiling proposal. Then I guess we are contacting both sides of Congress.   
  
So I'm wondering about the immediate action steps.   
  
The second question is I am wondering â€“ I read stuff from the center for budget and policy, they made the point particularly throughout the narrative, and then in the section they have one people with disabilities were going to be impacted.   
  
They basically said if you are NSFI (?) eligible for Medicaid, that you were exempted from the provisions of the work reporting requirements. That it sounded like maybe it was people who were either in Medicaid expansion programs, perhaps the buy-in, and also in the medically needy categories.   
  
So if our legislators either at the federal level, or because these requirements welcome to the state level eventually. If their past. Of course they won't be.   
  
I think we're going to have to explain to our US senators who is really impacted, and why even that is a big concern. I think you've done that part with the buy in here today.   
  
I'm concerned with is providing the message that deters all the arguments from the conservative side. So I was looking for guidance on the next steps which I would appreciate.   
  
JESSICA PODESVA:   
Sure, I will do my best to answer that. I think I have all of your questions down.   
  
The first part was on who to contact. Right now the house is in negotiations with the White House. This is still on the table for the Debt Ceiling, that's why one of the asks or to remove it off the table for the Debt Ceiling in negotiations. So we need to contact both sides.   
  
The Senate so the Senate stay strong and sides with the White House that these things are off the table, and the house so the house will fall. -- Fold.   
  
We need you to contact both sides right now. We need to contact the Senate to make sure they stay strong and they don't bend, and that the house kind of feels the pressure from the two branches.   
  
The second part of your question, it is really hard â€“ and I'm still grasping with this myself and have done so much reading on this issue. To know what that ripple effect look like, especially because it is so different in every state. I take the message is clear that the systems are incredibly complex, and any red tape in one has a ripple effect on all the others.   
  
I think the messaging for this particular crisis is these are complex issues that should not be rushed and used as a bargaining chip integrations like this. If you want to tackle some of the various firms limit for people with disabilities, we welcome that conversation and we will work with you in order to expand access to Home and Community-Based Services, expand access to employment, leverage Center for Indepedent Living. We will have that conversation. I think the point is to stop using and threatening people's healthcare as a bargaining chip to save a couple of dollars in the budget.   
  
And I'm sorry, now I'm getting overheated, but that I think is the message we need to stick with. Door is happy to chat further and talk through some of these more policy focused questions, but it's hard for me to answer because I do think it will look different in every state. Everything states like Oklahoma will feel a lot more than my state of Massachusetts.   
  
It is a very complicated ecosystem. I hope that clarifies and at least attempt to answer some of your questions.   
  
Next, Richard Gallo.   
  
SPEAKER:   
Yes, hello. We all need to make noise. We need to educate our federal elective officials, not just adults, but children with disabilities as well, because there are families that depend in-home support services, so it will impact families.   
  
JESSICA PODESVA:   
Very much so.   
  
SPEAKER:   
We all need to do in memory of Judy Mama, the mother of the disability rights movement.   
  
I put the no pity (Unknown Term) in the chart. For those of you who aren't aware of her, or to learn about the disabilities rights movement, we all need to band together. We are all in unity. We are a team. We must support each other to educate our federal elected officials.   
  
I've been disgusted with politics for the last 12 years, and I'm even worse now, but I still use the broken record in writing to my federal elected officials the importance of Medicaid.   
  
I recently wrote to the secretary of health and human services for the state of California reminding them to keep the Medicaid buy-in program, because the state of California is facing budget deficit in the next three or four years, and they are going to make cuts.   
  
Medicaid buy-in isn't access to healthcare, it's access to in-home support services, that's why it's critical. So let's all band together and make some noise. Thank you for   
  
JESSICA PODESVA:   
And that leads into one of my favorite Jlo songs, time to get loud.   
  
Lloyd we have another question, but before you go can I just tackle a couple questions in the chat.   
  
The first question I want to touch is will this be lobbying? Potential yes. You can do it in a way that's education. If you have questions on how to navigate that we have a great lobbying versus education guide that we can send out.   
  
Jenny can you post the link to that, I believe we have it posted on the 545 website. Words on the Nickel website, if someone can look that up and get that into the chat. We have a great guide that can help you walk that line if you are a center staff and afraid of crossing it.   
  
The second question is will Be providing talking points for committee Kini with our elected officials, the answer is yes.   
  
After the meeting we will send out a toolkit from the disability nation collaborative with information that I think â€“ I'm not going to reinvent the wheel, Michael does a great job summering up -- summing up the talking points on this. We will send that out. Also encourage you all to attend the rally tomorrow, and we will send out information for that as well. The more places we come together the better.   
  
I think that was it, Lori do you want to jump in?   
  
LORI TAYLOR:   
I just have a little piece of Lori advice. Richard, Jeff and a few others of us on this meeting had to protest, like I said, in the past. Because they were going to cut our Medicaid services.   
  
And by the way, contact your local or state adapt, they will help with messaging too.   
  
Anyway, on that. Don't be afraid to let your passion for this show. Because it is life and death. And let them know. You want them to look you in the eye if possible. And have them â€“ just be passionate, don't be afraid of it.   
  
Another piece of advice, it's mostly Republicans we will have to convince of this, because they are the ones trying to do it. They like talking about money. Just show them how backwards it is that the more peoples that they cut, the more people that are going to need the services. It doesn't make any sense.   
  
If you let the system work like it is supposed to, and expand it even more, we will all be happy. They will have more money in their pocket to do whatever they want with, and we will have independence and all that.   
  
Don't be afraid of the passion, that's my only message.   
  
JESSICA PODESVA:   
I love it Lori, thank you for sharing that.   
  
We have about nine minutes left, anyone else have comments or questions? Would love to hear from a few more folks.   
  
SPEAKER:   
I have a question.   
  
Sorry, I'm on the phone. I was just wondering, you may have said it already. I know we want to get to our legislators right away, but I was wondering what the supposed timeframe is for the Debt Ceiling legislation to continue along in the house. What the timing is for what we are trying to address? What is the timing on their end in Washington?   
  
JESSICA PODESVA:   
Right now the debt ceiling will reach that limit either by May 31 or if we hit I think it's 1.5 trillion, whichever comes first. So time is really of the essence. A lot of the negotiating is happening this week, which is why we are wrapping it up this week.   
  
Over the next few days, that's really the time to wrap it up.   
  
And then as it progresses, and we will share more information as that changes or any extensions happen, as this... We will share more as it goes. Really over the next few days wrap it up.   
  
SPEAKER:   
OK, would it be possible to, and you may have already done this.   
  
I know a lot of people â€“ my husband and I are both disabled. Participate in different support groups.   
  
Is there a way someone or you guys could send out an email specifically for us to be able to forward to groups of people who may not be in this loop or may not be aware, or might be able to take action to say, "Hey, I just participated in this workshop and this is what is going on. This is how you do something about it."   
  
JESSICA PODESVA:   
After this meeting ends we will send out something with all the toolkits. You can feel free to forward the action alert wherever, if you work for a center of independent living, one great way to get around the lobbying versus advocacy piece is simply share Nickel's action alert with what's going on.   
  
That's going out this afternoon, what has already gone out. If you are on the Nickel mailing list you should have received it, it was part of the legislation link for this rally. It also has information to contact your representative. We will be sending out a beefier toolkit this afternoon.   
  
And it will have information for the disability and aging collaborative rally tomorrow.   
  
SPEAKER:   
OK, thank you.   
  
JESSICA PODESVA:   
The phone is 7673, I think it's torus.   
  
SPEAKER:   
This is Doris, I remembered something else we might want to advance for Nickel. And it's this.   
  
The Center for budget policy made the point the reporting requirements, reporting requirements, then people will be put under are burdensome and in fact the online systems for doing that in the trials. This kind of reporting theme -- thing in Arkansas, trying to remember the state. Proved that software you have to use, the applications and portals are not accessible. They don't even meet 504, 508, and ADA requirements. And yet they are going to put people in jeopardy of getting some income that's helping them to maintain independent living, independent lifestyle, so they can even try work which is the whole point of the Social Security work incentive program. And in fact they are working against the Social Security work incentive program.   
  
I am hoping that putting a fire under all members of Congress no matter their affiliation, that what's being proposed puts an unfair and discriminatory burden on people with disabilities â€“ people with physical and sensory disabilities and other disabilities who are going to miss these reporting deadlines and will be cut off of the only income they have.   
  
Let's face it, SSI, which entitles you to Medicaid. It's only $940 and nobody can get it without help, no one wants to live on that.   
  
JESSICA PODESVA:   
Thank you Doris for sharing that.   
  
SPEAKER:   
And also I think of Congress had listened and had the guts to implement (Indiscernible) or what it was called before that, CCA, we wouldn't be in this position of jeopardizing both personal assistant services and CME and the rest of it. That should be taken out of the picture altogether.   
  
JESSICA PODESVA:   
Thank you for sharing that. We (Indiscernible) enter local legal aid brought up a pretty substantial lawsuit against them, and they have done a whole bunch of stuff to up their accessibility as a result. If you are encountering that interstate I urge you to reach out to your local legal aids, and organize around that. Because that's a really big issue, so thank you for raising that.   
  
We are almost at time, I want to bring us home. Comparedto the overall message is to get loud. Be aware of action alerts and stuff that's going to be coming out. Attend the rally tomorrow, get all your friends to attend the rally, your coworkers. Really live in that room up. And get on the phone and start calling representatives.   
  
Again if you have questions what constitutes advocacy versus lobbying, we have a great document that illustrates it. I believe there is also a hotline we've referenced in that. If it isn't referenced in that feel free to give me any more. There was a hotline number I can give you you can call. If you have a question whether or not you are crossing that line, they will be able to give you advice and tell you. So feel free to reach out to me on that.   
  
I think that is it, thank you so much for coming. Contact your representatives. You all have marching orders. We appreciate you all taking time out of your day to join us here this afternoon. Thank you so much.   
  
And I'm just going to make sure we save the chat Jenny and we stop the recording before we close out the meeting.   
  
Thank you everyone, and biggest thank you to respeakers for telling their story today.   
  
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